VOR
Speaking Out for People
with Mental Retardation

Toll free
877-399-4VOR

Website
http://www.vor.net

Govt Relations/Advocacy
P.O. Box 1208
Rapid City, SD 57709
605-399-1624 voice
605-399-1631 fax
Tamie327@hotmail.com

Washington, D.C.
529 Bay Dale Court
Arnold, MD 21012-2312
410-757-1VOR phone/fax
LarryInnis@aol.com

Tax Deductible Dues/Contributions
836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
605-271-0445 fax
husoj@sio.midco.net

August 17, 2009

Ms. Cindy Mann
Director, Center for Medicaid & State Operations
Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services
200 Independence Ave., SW, Room 445-G
Hubert H. Humphrey Building
Washington, D.C. 20201

Attn: File Code, CMS-2296-ANPRM, Medicaid Program: Home and Community-Based Services (HCBS) Waivers, Federal Register, June 22, 2009.

Dear Ms. Mann,

VOR is a national advocacy organization representing individuals with mental retardation and developmental disabilities (MR/DD) and their families. We very much appreciate this opportunity to comment on regulation which will impact our family members for decades into the future.

VOR strongly supports a continuum of quality care options to meet the wide range of needs, ranging from family home, own home, other community-based options, to Medicaid-licensed facility-based care (ICFs/MR). VOR is the **only** national advocacy organization representing the interests of individuals who choose and require ICFs/MR support. The provision of a range of service options is supported by federal law, including Medicaid and the U.S. Supreme Court (*Olmstead*).

I. Stakeholder input

VOR applauds the Centers for Medicare & Medicaid Services (CMS) for its cautious approach to rulemaking, and utilizing for the first time its advance comment authority. The issues raised in this ANPRM are serious and deserve careful contemplation and stakeholder input.

VOR expressly requests the opportunity to participate in the referenced "deliberative stakeholder process for developing criteria for home and community standards." (ANPRM, p. 29545).

II. The Olmstead Decision and Individual Choice

The ANPRM states that –

> "Many States have used the home and community-based services waiver as a component of their *Olmstead* compliance efforts and we are interested in receiving comments about how this change may affect these efforts. We are intending to propose this change in an effort to remove barriers to person-centered, needs-based service delivery methods." (ANPRM, p. 24953).

Although *Olmstead* is frequently cited as requiring deinstitutionalization, the Supreme Court actually called for the provision of person-centered supports based upon professionally assessed needs and individual choice, while also considering available state resources (*see*, 119 S. Ct. 2176, 2181 (1999), *holding*). With regard to whether "institutional" care is appropriate for anyone, the court was very, very clear:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. (*Olmstead* at 2187).

Olmstead, and its requirement for individualized supports, was at issue in a recent Illinois case. *Ligas v. Maram* was originally filed by nine individuals who claimed that Illinois had not provided them with the community-based supports that they had requested and were eligible for. These few plaintiffs sought remedy for their individual claims, and sought to speak for a class of 6,000 developmentally disabled individuals. The Court recognized that a class of 6,000 could not have homogenous needs. Thus, the remedy sought by the nine plaintiffs – community integration – failed the *Olmstead* test which requires consideration of individual need and choice:

> A common theme among the [more than 2,500] objectors was the concern that many developmentally disabled individuals, who are within the class definition, would be adversely affected by provisions of the Proposed Consent Decree even though the individual neither met the *Olmstead* criteria nor desired placement in a community-based setting. [*Ligas*, Case No. 05 C 4331 (July 7, 2009)].

The Supreme Court, and more recently the *Ligas* court, recognized what we family advocates have always known: neither institutions nor community settings alone can meet **all** the needs of **all** people with developmental disabilities **all** of the time.

In any final rule, CMS is cautioned not to overstate – as so many advocates and even state officials have – what *Olmstead* actually requires. *Olmstead* stands for choice, not the elimination of choice through downsizing and closure of facility-based care.

III. VOR Comments: Same Waiver for Different Disability-Types and Defining Community

VOR herein submits our comments on the two issues which are the subject of this ANPRM:

A. Removing the Regulatory Barrier to Designing 1915(c) Waivers Based on Needs Rather than Diagnosis or Condition.

State funding and service flexibility must not come at the expense of the individuals being served. The proposal to allow single waivers to serve different disability types based on similar service needs raises several questions and related concerns, including:

1. Will the regulation to allow single waivers for people with different disabilities expressly prohibit serving different disability types "under the same roof?"

VOR is concerned that the primary objectives of equal access to service, regardless of disability-type, and fiscal efficiency will lead to providers mixing populations with potentially disastrous consequences.

The ANPRM is not clear on whether a regulation to allow for single waivers will include a prohibition against serving different disability-types in the same service setting. Failure to protect against comingling incompatible disability populations presents serious and foreseeable risks to beneficiaries being served. Fiscal constraints could well tempt a provider to mix populations and accept residents that are not well suited for the existing client mix or the homes' accessibility.

This is already happening in some states. For example, Wisconsin allows residential providers to serve multiple populations. In one case, a provider is licensed for 19 people, male or female, for all populations: elderly, alcohol/drug dependent, developmentally disabled, and emotionally disabled/mentally ill. Problems mixing populations are well-documented:

> In **North Carolina**, Ruth, an 84-year-old resident of a small, quiet elder care home was brutally stabbed by another resident, age 25, with severe mental illness. He was placed in an elder care home despite his well-documented history of violence.
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> In **Florida**, M.C., a 48-year-old woman with mental retardation, schizophrenia, and heart problems, was raped by another resident in her group home, a 16-year-old who had a history of sexual assaults but had always been declared incompetent to stand trial. Following the rape, M.C. was taken to the hospital after suffering "episodes of vomiting." Shortly after her release from the hospital, she died in her group home.
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> In **Washington, D.C.,** Michael, a 52-year-old resident of a group home for the mentally ill died after being attacked by another resident with a fire extinguisher in a fight over cookies.
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> In **Wisconsin**, a community-based "geared toward serving an elderly population" with a minimum age of 55 years old, admitted residents who "were not compatible with the facility clients served," including a suicidal 16 year old and a 19 year old who had a history of violence, according to state Quality Assurance Reports. In one case, a younger resident's behavior got "increasingly worse and is to the point where it is a great disturbance to the other residents," including an instance where she was "yelling, screaming, upsetting the other residents [because her bus was late] . . .Her temper escalated until she started throwing coffee and water at the other residents, screaming vulgarities at [staff] and residents, and threatening to hurt herself, the residents and [staff] and run away."
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> In **Massachusetts**, Claudia, age 53, has mental retardation and is legally blind, non-verbal, and has had medical complications and behavioral issues. Citing financial savings, her group home was closed and she was transferred to another home with a swimming pool and three other residents, all of whom used wheelchairs, despite her mobility, blindness and behavioral concerns.
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> In **Florida**, a healthy baby was born to a severely mentally disabled mother, who was referred to in documents as "J.D.S." and was tragically raped in an Orlando, Florida, group home where she lived.

> In **Florida**, the mother of G.C. complained that her boy, who could not communicate, "appeared to be over-medicated when she took him home for Thanksgiving," and that she was concerned about a bite mark on his face. The Jackson Rape Treatment Center personnel "diagnosed anal penetration," possibly by G.C.'s roommate.

The tragedies described occurred in small group homes. Some large ICFs/MR (“institutions”) have accepted court-ordered individuals whose disabilities render them incompetent to stand trial or, because of their disability, cannot be held criminally responsible. Due to the bias against ICFs/MR, in some cases, new admissions are limited to these “forensic” placements. Predictably, when residents accused of violent offenses live with each other, and also with the very vulnerable traditional residents, tragedies can and ***do*** occur:

> In **Maryland**, a resident, whose placement at an ICF/MR was court-ordered and who was known to make racist comments lived in the same cottage with an individual who became enraged by the comments, and beat him severely.
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> In **Ohio**, an ICF/MR resident (Edward, age 20) with a history severe aggressive behavior was placed as a roommate to an autistic individual (Joseph, age 50) who also had a history of violent outbursts. Edward killed Joseph by wrapping a belt around his neck and strangling him.

As these examples illustrate, foreseeable injuries, abuses and deaths are inevitable. Even more “benign” scenarios are predictable: An elderly resident with dementia is placed with a profoundly developmentally disabled roommate; an individual with physical disabilities is placed with someone with mild mental illness; an individual with severe autism is placed with someone with profound developmental disabilities who is unable to defend himself or recognize danger. The individual pairings in these scenarios may well have very similar ***functional*** needs, but what about their interests, their peers, their health care needs, their “community.”

To achieve legitimate person-centered planning and to adhere to *Olmstead* directives, need and disability diagnosis are both fundamental factors to be considered. A focus on need alone could well lead to totally incompatible people being served at the same residence. If CMS removes regulatory barriers to combining target populations in one waiver, CMS must expressly prohibit using these waivers to serve different populations ***in the same location***.

2. **Will the new regulation protect against a scenario in which a state opts to use its single population waiver funding to serve the most people it can, at the expense of the most needy, most costly of the population?**

Presumably, the purpose of removing targeting requirements to allow for one waiver for different disability-types is to enhance access to services and make the provision of services more equitable across disability lines.

VOR fears that the blending of target audiences could have the opposite impact, and leave the “voiceless” minority without access to adequate services. Consider a waiver that includes aged beneficiaries and individuals with mental retardation. The institutionally-eligible elderly population far outnumbers ICF/MR-eligible individuals with mental retardation. The elderly are far better positioned to lobby for and receive necessary supports.

A state looking to demonstrate that it has served more people with a targeted approach could well be tempted to serve the most at the expense of a few, while also serving incompatible populations in the same service setting, as discussed above.

3. **Will the new regulation protect against a triage approach, in which the most needy get served first at the expense of the less needy?**

   Even if a state does right by its most needy, the CMS objectives of fiscal efficiency and equitable access will be thwarted.

B. Defining "Home and Community-Based Services

1. Stakeholder Involvement

The ANPRM indicates that CMS "does not contemplate specifying criteria for home and community-based standards in the proposed regulation," instead opting to "solicit stakeholder interest in working with CMS to develop policy guidelines for State definitions."

VOR appreciates this cautious approach and **expressly requests the opportunity to participate in discussions to develop policy guidelines for state**, relative to defining HCBS. VOR will lend an often overlooked perspective to these discussions: the perspective of ICFs/MR residents and their families.

2. Overreaching Technical Assistance

We strongly object to CMS' intent to provide "technical assistance" to states that address "mechanisms for reducing the size of existing larger residences, divesting themselves or helping their providers divest themselves of sizable properties, and assisting providers' transition to smaller, more individualized settings." (ANPRM, p. 29454). What constitutes a "larger residence?" Is this "technical assistance" a push for self-determination and both an incentive and an excuse for the state to phase out funding for necessary programs for people with severe disabilities? If so, this appears to be a clear "community imperative" to states that is not in keeping with *Olmstead* and other federal law. As noted above, a federal court recently held that Olmstead requires consideration of individual needs and choice and that failure to consider each individual's needs and desire for community living ("reducing the size of larger residents"; "divest themselves of sizable properties"), violated *Olmstead*. [See, [*Ligas*, Case No. 05 C 4331 (July 7, 2009)].

Smaller settings do not automatically ensure "optimal choice, control, and community integration." (ANPRM, p. 29455). Just the opposite is often true: Smaller can be isolating, as discussed in the "*Isolated Communities*" subsection, below.

3. Market Demand?

The ANPRM states that CMS intends to adjust the regulations to describe expectations with regard to waiver participants being served in the home and community, believing that this will "increase choice by providing waiver participants with notice of housing alternatives, and would create greater demand and market incentive for person-centered residential settings." (ANPRM, p. 29454).

There are more than 200,000 people waiting for services, the majority of whom would choose home or community-based services, if appropriate services were available. "Demand and market incentive" for community based supports seems well in hand. VOR is unclear how federal guidance on "person centered" housing alternatives will result in more housing where it is now lacking. How will additional federal requirements entice new providers to meet the currently unmet need?

4. ICFs/MR as inclusive communities

ICFs/MR residents and their families overwhelmingly view their ICF/MR homes as a community in every sense of that word. They resent the frequent implications that ***all*** ICF/MR residents are isolated and do not receive person-centered care and that ***all*** residents of small homes automatically benefit from "inclusion." Consider these perspectives:

> "'The Glenwood Community School District, serving school children from pre-school through high school, shares the same campus as Glenwood Resource Center [a state operated ICF/MR]. There is also a workforce development center, a domestic violence shelter, offices for the Department of Natural Resources Conservation and Forestry, a variety of University training and research programs, and much more on the Glenwood campus,' shares Finken. 'If that's not integrated, I don't know what is.'" [*Glenwood Opinion Tribune*, April 30, 2008].
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> "Like Florida seniors and others who embrace planned communities, residents of Florida's residential campuses for people with profound mental retardation - Gulf Coast Fort Myers, Sunland (Marianna) and Tachachale (Gainesville) - have safe and comfortable accommodations, with ample opportunity to socialize with peers and neighbors. They receive compassionate life-sustaining support from specialists and direct care staffers, some of whom have worked with residents for decades . . . families embrace a "one size does not fit all" motto, pointing to choice and need as paramount. For some people with mental retardation, a small neighborhood setting, with minimal supports is the better option. For others, onsite specialized services such as dental, medical, therapy, work programs, religious services and recreation, are needed." [*St. Petersburg Times*, "Check with families first before evicting residents," February 5, 2007].
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> "[W]hen Mary Elizabeth lived at the ICF/MR, she was one of four or five individuals in a dining group who regularly went to local restaurants with staff from the facility. These staff scouted out local restaurants in which the typical food is easily consumed by those who have problems with chewing and swallowing (e.g., local spaghetti or fish houses), and even brought a food grinder along for those who required that their food be blended . . . Now, at least once a week a group of three to five of the ladies in the day program (most of whom live at the ICF/MR) go to Dunkin' Donuts for mid-morning coffee. They go out another day each week on an excursion that may be a picnic at a local beach, lake or park. In the winter they go to the local malls and shop for small personal items. They are seldom deterred by New England weather. Annually they go to the New England Flower Show in Spring, the Nutcracker ballet at Christmas, and Topsfield Fair in the Fall. ["Outcomes that matter: A parents' perspective," ("Mary Speaks" section) *Mental Retardation,* Volume 43, Number 3, pp. 214–220 (June 2005)].

> The Turtle Creek Youth Program at the South Dakota Developmental Center (SDDC) serves 40 behaviorally challenged, school-aged children who are between 10 and 21 years of age at the time of admission to the center. All youth attend school on the campus of SDDC in a building designed for classroom teaching. The Redfield Public School provides the educational program, including the employment of special education teachers. The curriculum is comprised of the core educational courses as well as several group curricula that are facilitated by Youth Counselors who are staff of the Turtle Creek Program. The group courses can be taken for elective high school credit. Once an individual completes the requirements for graduation, he or she participates in the graduation ceremony at the public school. (*The Voice*, Winter 2008).
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> "By 2009, I am happy to report that the detractors of the original project, from all areas, have been proven wrong. The Underwood and Lee Clinic [located at the Hazelwood ICF/MR in Louisville, Kentucky] now serves over 820 patients [nonresidents] from 44 counties in the state. By the summer of 2010, we expect to be serving over 1000 patients. Despite the fact that some of our patients drive 4 to 5 hours each way to access care at our clinic, we have a 97.2% patient satisfaction rate . . . The Underwood and Lee Clinic's research program established, early on, that it was not performing redundant care. Frequently, the clinic would see patients who had been unable to access adequate care for over 10 years. Some patients arrived at the clinic with more than a dozen painful dental abscesses in their mouths – a testament to their long-standing inability to find care at any other medical or dental facility in the state. . . . The teaching program at the clinic has positively affected the entire community of dental providers in the state. Since inception, nearly 500 dental students and dental hygiene students have rotated through the clinic, learning how to care for our special patient population." [Matthew Holder, MD, MBA, CEO, Underwood and Lee Clinic, March 24, 2009 (letter)].
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> In Massachusetts, one-third (11,000) of all Department of Developmental Services clients use the six state developmental centers (ICFs/MR) for health and dental care, services which are not available in the community from private practice physicians. Closing these centers will put an undue hardship on the clients, their families, and the staff who care for them. (David Hart, President, MA Coalition of Families and Advocates, August 14, 2009).

Around the country, ICF/MR campuses are used by their neighbors for summer camps, soccer practices, school gatherings, fairs, and more. Some ICFs/MR also extend their professional health care services and amenities (such as therapeutic swimming pools) to nonresidents who would not otherwise have access to these services. Some campuses also offer teaching opportunities to area college students (*e.g.,* Northern Virginia Training Center, Tachachale Developmental Center (Florida), Hogan Regional Center/REACH program (Massachusetts), Hazelwood ICF/MR (Kentucky), Central Wisconsin Center and others.

5. Isolated Communities

Likewise, typical notions of what constitutes "community living" do not always equate to "optimal choice, control, and community integration." (ANPRM, p. 29455). The following examples, and many more like them, are what worry parents and family members and suggest a lack of correspondence between the promise of community living and the reality:

> "[C]ommunity activities at the group home are 'spontaneous' and left to 'staff discretion' (what happened to client choice?). The result is that everything (quality of diet, exercise programs, clothing, holiday celebrations, health care and community participation) depends on the spirit, initiative and endurance of the house manager. In too many instances house managers receive little support and constant obstacles from their superiors. As a parent observer, it often seems to be an impossible job. When there are no planned community activities on a weekend, evening or holiday, residents sit, often isolated, alone in their rooms, sometimes for 2-3 days in a row. How is this more desirable than sitting in a group with staff at the facility?" ["Outcomes that matter: A parents' perspective," ("Mary Speaks" section) *Mental Retardation,* Volume 43, Number 3, pp. 214–220 (June 2005)].
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> "Dennis was a beautiful sweet person, and needed to be supervised 24/7. He had lived in group homes his whole life. His provider received funding for 'independent living' and moved Dennis into this program. Dennis was killed 1 month later, while crossing a 7 lane intersection by himself." (Anonymous, August 2009).
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> "A long-time participant in our Sunday School for Exceptional Adults stopped coming regularly when he was placed in a community residence. With the one caregiver on duty per shift, if one of the three residents doesn't want to, or is unable to come, to Sunday School, or any outing, all must stay home." (VOR advocate, August 2009).

Furthermore, a regrettable reality is the fact that many "neighbors" are not welcoming of these homes and their residents. NIMBY ("*Not In My Backyard*") often prevails and is an isolating factor that cannot be ignored.

6. Adequate oversight for all HCBS waiver providers

The ANPRM states,

> "[W]e are planning to propose adding to 42 CFR subpart G a requirement that individuals receiving HCBS waiver services must reside in the home or community, in accordance with either of two criteria enumerated below:
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> > "Resides in a home or apartment not owned, leased or controlled by a provider of any health-related treatment or support services; or
> >
> > "Resides in a home or apartment that is owned, leased or controlled by a provider of one or more health-related treatment or support services, and that meets standards for community living, as defined by the State and approved by the Secretary.
>
> "We believe that this wording takes into account the variety of living situations that should be exempt from evaluation, and avoids indirect indicators such as number of residents. Only living situations in which a paid provider of services has opportunity to affect the degree of independence and choice will trigger application of additional State-defined and CMS-approved standards for community living."

VOR feels strongly that ***any*** service provided through an HCBS waiver must be subject to the same level oversight, even when the beneficiary resides in a home "not owned, leased or controlled by a provider." A resident's name on a lease should not exempt the provider of his/her life-sustaining services from the same level of oversight as any other provider of HCBS waiver services.

7. Defining Community

The ANPRM indicates that CMS does not "contemplate specifying criteria for home and community standards in the proposed regulation," and will instead develop policy guidelines.

Although VOR questions whether "community" can be adequately defined in the first place, if a definition is pursued, VOR supports a **federal** definition of HCBS, rather than deferring to the states the determination of what constitutes "community" (thus risking 50 different definitions).

If and when "home and community based services" are defined, VOR urges the consideration of a definition of "community" that is consistent with typical usage, rather than what that term has come to mean in the disability arena and reliant on irrelevant tangibles such as residence size, distancing requirements, location, and type.

Webster's defines Community to include, "a unified body of individuals" and "a body of persons or nations having a common history or common social, economic, and political interests."

In this typical sense, "community" relates to rights, happiness, convenience, comfort, safety and access. It is not a term that can be fully and adequately defined using solely tangible criteria. "Community" means non-isolated environment where one is safe from harm and has consistent access to a social network of peers, friends, supports (informal and formal, such as healthcare, work programs, and transportation).

IV. Conclusion

We appreciate the opportunity to submit these comments. Thank you for your thorough consideration of the important concerns we have raised with regard to the two main issues raised by the ANPRM: (1) the foreseeable dangers of mixing incompatible people with disabilities, tragedies that are inevitable if single waivers for different target populations are allowed with prohibitions on placing incompatible people together; and (2) the difficulty in adequately defining "community" and the dangers of too narrow a definition. We appreciate your review.

Sincerely

Robin Sims, VOR President
582 E. Passaic Ave.
Bloomfield, NJ 07003-4416
973-338-7266 home
973-517-1126 cell
rsims23@aol.com

Sam Golden, Chair
VOR Govt. Affairs Committee
1700 E. 56th Street
Chicago, IL 60637-1370
770-288-3459 phone
s-golden@uchicago.edu

Tamie Hopp
Director, VOR Government
Relations and Advocacy
P.O. Box 1208
Rapid City, SD 57709
605-399-1624 direct
605-399-1631 fax
Tamie327@hotmail.com